

*Citation for published version:*

Valentine, C & Walter, J 2015, 'Creative responses to a drug- or alcohol-related death: a socio-cultural analysis', *Illness, Crisis, & Loss*, vol. 23, no. 4, pp. 310-322. <https://doi.org/10.1177/1054137315590733>

*DOI:*

[10.1177/1054137315590733](https://doi.org/10.1177/1054137315590733)

*Publication date:*

2015

*Document Version*

Peer reviewed version

[Link to publication](#)

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## **For Special Edition of Illness, Crisis, & Loss**

### **Loss, Bereavement and Creativity**

#### **Creative responses to a drug or alcohol-related death: a socio-cultural analysis**

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#### **Abstract**

This article takes a socio-cultural approach to examining creative responses to a traumatic death and loss and their contribution to further understanding of grief, identity and post-mortem bonds. Based on qualitative interviews with family members bereaved after a drug or alcohol-related death, the article explores how, in circumstances which threaten identity and continuity of being, grief may find expression through public and private creativity. Indeed, such creativity was apparent despite negative cultural representations of such deaths invalidating the grief of those left behind, who may suffer profound guilt, isolation and disturbing memories. Whilst interviewees reported such negative effects, psychologically considered symptomatic of complicated grief disorder, they also conveyed creative responses to negative stereotypes, rebuilding identities and continuing bonds. These responses, through which interviewees communicated both vulnerability and resilience, revealed a complex and nuanced picture of grief following traumatic loss.

#### **Introduction**

This article considers how creative responses to traumatic loss may further illuminate the relationship between grief, identity and continuing bonds with deceased loved ones

(Klass et al., 1996; Valentine, 2008). More specifically it analyses qualitative data from six interviews drawn from a sample of one hundred<sup>1</sup>, in which participants conveyed their experiences of mourning a drug or alcohol-related death. Since the potentially disintegrative nature of bereavement offers a valuable focus for examining the human capacity for creativity, it may be argued that the devastating nature of this type of loss (Feigelman et al., 2012) brings this capacity into sharper focus. This article therefore examines and illustrates, in circumstances which pose a profound threat to identity and continuity of being, the extent to which individuals may find creative ways of responding to their predicament.

In shedding light on creative responses to a prevalent<sup>2</sup>, yet neglected<sup>3</sup> bereavement, this article takes a socio-cultural approach to a topic that has mainly been studied from psychoanalytic, therapeutic and mental-health perspectives<sup>4</sup>, particularly the role of the arts in working with bereaved people (see e.g. Buser et al., 2006) and studies of artists whose work has been inspired by grief and loss (see e.g. Mahon, 2009). In placing creativity in the context of the relationship between individual and society, this approach foregrounds how individuals negotiate predominant social and cultural norms in light of their own personal circumstances, however traumatic these may be. In focusing on a particularly vulnerable group, this perspective captures the way cultural norms are not determinative, but rather open to interpretation by individuals,

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<sup>1</sup> [go.bath.ac.uk/bereavementresearch](http://go.bath.ac.uk/bereavementresearch)

<sup>2</sup> In Britain, in 2011, 8,748 alcohol-related deaths (ONS, 2013) and 1,785 drug-related deaths (Davies et al., 2012) were identified, though actual figures are likely to be higher than suggested by official statistics because, for example, some deaths are not recorded or categorised as being alcohol or drug-related, and definitions of such deaths tend to vary.

<sup>3</sup> To date there has been little focused research or guidance for providers of addiction or bereavement services.

<sup>4</sup> One exception is Walter's article (2012), which draws attention to the lack of understanding of 'lay' creativity in the everyday lives of those who are dying or grieving outside formal medical and care situations.

who may actively contribute to shaping culture (Seale, 2000; Long, 2004; Valentine 2009).

Such norms include mixed and competing cultural messages about, for example, how one should grieve or a death be handled, and may be experienced as both providing resources and imposing constraints, as well as, to a greater or lesser extent being open to negotiation. One culturally approved resource entails finding some thread of continuity in a situation in which one's 'assumptive world', including sense of self, both personal and social, has been shattered (Parkes, 1988). Finding such a thread has been found to benefit significantly from particular forms of social support (Rosenblatt, 1993), including being able to share one's experiences with sympathetic others, either informally with those who knew the person (Walter, 1996), or more formally through membership of a bereavement group (Walter, 1999). It may include various forms of memory-making (Hallam and Hockey, 2001) and developing a continuing bond with the deceased person (Klass et al., 1996; Valentine, 2008). Taking comfort from fond memories has, in turn, been found to depend on social support and sharing with others in a way that provides understanding and validation of one's loss.

Grieving norms have also been found to reflect the extent to which a death is considered 'good' or 'bad' (Seale and Vandergeest, 2007), with some 'bad' deaths attracting social and moral condemnation from the wider society. Substance-related deaths are particularly vulnerable in being perceived as self-inflicted, as well as linked to a deviant life-style, which, in the case of drug use, may involve illicit activity (Feigelman et al., 2012; Guy, 2004). Such attitudes may be reinforced by tabloid representations of the deceased person as having brought about their own death, such reporting tending to encourage the reader to distance themselves from, rather than empathise with,

surviving family members (Guy, 2004). Rather, the family may be considered complicit or dysfunctional, their grief 'disenfranchised' (Doka, 2001) because the death is not considered worth grieving. This attitude may exacerbate feelings of guilt and self-blame for failing to have prevented the death.

Stigma may prevent those left behind from confiding in sympathetic others making it much harder to find meaning and continuity in the face of loss. As one mother from our study reported when talking about her son's death from alcohol misuse, this constraint could be experienced within the family.

*"My sister never said anything about him, you know, a lot of people think well he caused his own death, you know...Oh well they brought it on themselves, you know, so I don't think you get the sympathy that you would get normally."*

Indeed, along with profound guilt and self-blame, this group of bereaved people are likely to suffer disturbing memories related not only to the nature of the death but also the stresses and strains of living with the person's substance misuse (Orford et al., 2010), which may hamper developing and taking comfort from a continuing bond. Rather the lack of opportunity to share their story, places them in a position of being alone with these experiences, a situation which may well have started prior to death.

From a psychological perspective, these experiences have been considered symptomatic of complicated grief disorder (Stroebe and Schut, 2005-6), which highlights the emotional and physical toll of traumatic loss. However, the focus on vulnerability is now being complemented by a focus, not only on resilience (Bonanno, 2009), but post-traumatic growth (Joseph, 2012). Whilst acknowledging the health risks of traumatic loss, this article shows how creativity can be part of post-traumatic growth. This

perspective reveals a mixed and complex picture of the way people grieve, in which vulnerability and resilience go hand in hand, including responding creatively to traumatic loss, to recover identities and **continuing bonds** (Klass, Silverman and Nickman, 1996; Valentine 2008).

### **Repairing Identities and Continuing Bonds**

Creative responses to traumatic loss are examined through data drawn from six interviews<sup>5</sup>, which form part of a much larger sample of 100 interviews carried out in Scotland and SW England between March and December 2013. The six interviewees included two mothers, two daughters, one niece and one brother; the deceased people they talked about included two sons, one father, one uncle, one mother and one brother (see table).

Interviewing was undertaken by three researchers, including the first author, experienced in researching sensitive topics. In this case, in addition to the emotional distress of recalling painful experiences that interviewees may experience, interviewers were also sensitive to concerns that members of this group may have about being stigmatised, potentially making them reluctant to share personal material. Thus, an open-ended, conversational approach was adopted, so that participants could disclose only as much as they could manage.

In addition to encouraging participants to tell their story, the interview schedule covered specific key areas, including the relationship with deceased before they died, the nature of the deceased's addiction, how the person died and the impact of the death on those left behind, finding support and memory-making. In focusing on these areas,

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<sup>5</sup>With data analysis being at a preliminary stage, these interviews have been selected and studied as representative of certain types of creativity found to be prevalent in the larger sample.

participants' responses conveyed the shattering impact of both living with a close other's substance misuse as well as coping with their death in a context in which their need for support could be met with insensitive treatment, even in the immediate aftermath. As one mother (from the larger sample) reported, her son having died of a heroin overdose, the behaviour of the police could be experienced as implicating the family in the death.

*And there seemed to be a lot of policemen and they said, "we're searching the house". I said, "have you got a search warrant?" He said, "we don't need a search warrant." I questioned how they could do this, but they were very sort of - they treated us terribly.*

Yet, at the same time, as illustrated by the six interviews, some participants were determined to make good what was initially felt to be unredeemable, something which required them to engage with, rather than remain victims of, those very areas of difficulty. Such engagement found creative expression in diverse and manifest ways, such as helping others in similar circumstances (Small and Hockey, 2001) writing autobiographical books (Holloway, 1990) and writing to the dead (Hunsaker Hawkins, 1999). Whilst engagement in these kinds of activities has been reported by bereaved people more generally, given the difficulties associated with grieving this type of death, as will be illustrated, such resourcefulness is both striking and poignant.

Interviews were analysed thematically, with the aim of capturing the way individuals negotiate broader socio-cultural processes. Thus, within the diverse creative forms, we identified three common, though interlinked and overlapping themes. These structure the following discussion of the creative ways in which participants were able to recover a sense of continuity in their lives, including repairing shattered identities and

continuing bonds. The themes are: 1. *Understanding and raising awareness of substance-misuse*; 2. *Supporting those living with or bereaved by substance misuse*; 3. *Developing a continuing bond with the deceased person*.

### *1. Understanding and raising awareness of substance-misuse*

The crucial role of remembering and piecing together the life of the deceased person in making sense of loss is well documented (Braun and Berg, 1994; Walter, 1996; Neimeyer, 2002) a process which, as indicated, may be particularly painful where that life involved substance-misuse. Yet, in the absence of opportunities to share their grief with others, whether professionals, friends or family, some participants found meaning through furthering their understanding of substance use more generally, enabling them to find and place the meaning of the deceased person's addiction in a wider context. This could be achieved through both informal and formal study, which enabled mourners to see beyond cultural stereotypes and the sense of personal guilt and self-blame that these may reinforce. For one daughter, Jennifer, who went on to train and support others living with a family member's addiction, the drive to understand why her mother drank was experienced as positive and life-changing.

*But for me I wanted to understand why she drank I think. And I don't have the answer to that but I think I've tried to understand a bit more about my family dynamic and why things are as they are, tried to piece together some of the things that perhaps weren't quite as they seemed...and learning.. I suppose going by how it's affected me in positive ways as well as negative ways... I definitely, you know would I change it? I would like some of the pain to have gone away but I do think the relationship I have with my mum has made me who I am and from that I have a lot of empathy and a lot of determination and it has enabled me to achieve things in my life that I may not have done otherwise.*



*As you only have 6 participants here –you should give them a name each and then readers can follow individuals through the article*

The motivation to understand thus extended beyond personal grief to find empathy with others. Another daughter, Katherine, whose father died from excessive drinking, conveyed how such empathy could find expression in a desire to increase understanding more generally of substance misuse and the suffering it may bring to both user and family. Prior to her father's death, as a teenager she had found herself becoming more and more interested in alcoholism to the point of studying this as part of her psychology 'A' level. She describe this as a "fascination", which reflected both wanting to come closer to what she saw as her father's suffering and find support in a context in which she felt unsupported by those around her.

*Looking back it's worrying how little support from school was there. We had nothing from any other services, kind of external services. The things that are kind of pinnacle in society and kind of systems in our society such as police and school and social services they were non-existent which I find surprising.*

Later on, as a teacher, Katherine felt she was in a position to do something more with her understanding of alcoholism that would benefit others.

*What I'm hoping to do kind of going on from the fact that lots of adults find it quite uncomfortable to talk about alcoholism and death through alcoholism I am hoping ...to start building educational materials for PSHE [Personal, Social and Health Education] so that teachers can kind of pull it off of the database or system...A good set of resources with backed up material, so they can feel more confident in teaching about alcoholism...*

Both Jennifer and Katherine initially struggled with self-blame and guilt at having failed to prevent their parents' excessive drinking and eventual death, before reaching a more complex and realistic understanding. This process entailed moving beyond popular assumptions of addiction and appreciating their own limitations in a situation for which they had blamed themselves. As a result they were able to make creative and material contributions to helping others who were suffering similar experiences. In so doing, they were also able to pick up the threads of their own lives, to recover a renewed sense of identity as well as repair their relationship with the deceased parent, whose predicament they were now able to understand and, to some extent, empathise with.

Such empathy could find creative expression through the desire to raise awareness by challenging negative stereotypes, which stigmatised and defined users only by their addiction. Indeed, the Katherine conveyed how her aim to provide educational materials was linked to dispelling such stigma.

*So making people more aware for me is important and not demonising the alcoholic... not demonising somebody who has an addiction and trying to help them.*

For a mother, Angela, whose son died of a drug overdose, responding creatively to negative stereotypes was crucial to being able to live with the loss. Thus she produced various articles and a book about her bereavement experiences, with the intention of dispelling preconceptions about drug users and encouraging others to share similar experiences rather than feeling silenced by shame. The expansion of autobiographical accounts of bereavement in the late 20<sup>th</sup> Century has been noted (Holloway 1990) both as a reaction to grief's privatisation as well as a reclaiming of ground from the medical professionals. However, as a reaction to the stigma associated with substance-misuse,

as Angela's experience suggests, the writing itself may be a more uncomfortable and challenging process.

*...I'm not so much interested in telling the story; I'm more interested in telling the story so that people who might have been- who might be like me and might have preconceptions about people who use drugs and the families of people who use drugs...And the stigma and the shame and all of that. By telling the story it's, you know, and then somebody else tells their story. And before you know it, it's no longer such an area for shame that people can be more open. I don't like doing it. It's just not comfortable with me. But it's only by doing that that you can say, and, you know, I'm proud of my son.*

In bearing witness to her son having achieved far more in his relatively short life than his drug use might suggest, Angela was able to remain positively connected to and take pride in his memory.

Darren, whose brother died of an alcohol and drug overdose, was hurt and angered by negative, stigmatising responses, which devalued the life of his brother and others like him, but also believed such responses to be rooted in lack of awareness. Before his bereavement, Darren had begun a degree in media studies, and following the death he decided to use his studies to explore substance misuse.

*..and it was going into the second year that I, kind of, started to use film and when my brother died, I was just going into my third year which is all self-motivated work ...and that's why I felt I was in a position at that point to do that, because that was the only thing on my mind....*

As a result he applied his film-making skills to portraying the complex human story behind the stereotypes.

*...the fact that you could say, well, it's better that they're dead than have somebody that uses in society and that.... I think that really affected me to the point where that's what really made me want to explore drug use further and understand it better and help... raise awareness of the fact that, you know, he was a person. So...I was doing a lot of work on drug-related deaths and trying to find out as much about that, speaking to police and practitioners and people that are still using and as many people as I could, using film, to try to gather all these stories together and make this film, sort of tackle ... those kind of stereotypes and ignorance and stuff in society.*

Thus both Angela and Darren found meaning in their loss through using personal and private grief in the service of a wider public and social agenda. In drawing on and further developing existing skills, they were able to recover and repair an important thread of continuity in their lives, which included both their own identity and that of the deceased person, as well as their relationship with them.

## *2. Supporting those living or coping with substance misuse and/or who have suffered bereavement as a result*

For some participants being unable to find support for their loss fuelled a desire to use their experience to support others in a similar situation. For Eileen, this experience arose from a complex and chaotic family situation as a child of alcoholic parents, as well as the alcohol-related death of her uncle to whom she felt particularly close.

*I was really, really close to him...Especially as I hadn't had the best childhood myself, so he seemed to be the one that understood me the most. If I had bad behaviour, he would understand it.*

Not only had Eileen experienced a lack of support when growing up with alcoholic parents, but also her grief after her uncle's death was not deemed to warrant any kind of bereavement support.

*...just because you're not a partner or a child, it doesn't mean that you're not going to feel it just as much."*

Yet, rather than remaining isolated, Eileen's experience of being alone with such painful and distressing feelings drew her closer to the plight of others in similar circumstances, prompting her to train and work as an online mentor with an organisation for supporting children of alcoholic parents.

*So, you know, there's lots and lots of children and young people going through that kind of thing, so I just really want to help them and be there so they can speak out, so they're not trapped and alone. And maybe speaking to somebody on [helpline] or speaking to me on [helpline] will give them the confidence to change more about their life and maybe get more help and get out of the situation. So that's why I really want to do it. And for me that just makes me feel better knowing I can have that impact in somebody's life.*

By responding creatively in terms of making a positive contribution to the life of those, like herself, whose support needs tended to be overlooked, she was able to recover a sense of personal effectiveness.

For Angela, who wrote about her son's death from a drug overdose, the experience of aloneness related to being unable to find a support network.

*I went on the internet and looked but for some reason, I don't know, maybe it wasn't searching well, but I couldn't find anything that was- I found a few helpful bits from a few mums, but I couldn't find anything what I might call mainstream – support networks. You know? I just felt so alone, so I didn't know what to do with it, really."*

Yet, in spite of feeling at a loss, like Eileen, she found a creative way to reach out to other similarly bereaved parents through her writing. By sharing her own and her son's story with others in a similar situation, she found support for herself.

*... I decided I was going to write a book, which I have subsequently done... it's rather a jumbly book, but most of all it is a book about loss and it is a book about loss by bereavement, by addiction, drugs... But, having said that, you know, I think a lot of people have found it helpful, actually. Loads of people have read it and said that's really helped me.*

For both Angela and Eileen, the experience of aloneness propelled them to reach out and connect with others in a creative and productive way rather than being defeated by the obstacles to finding social support. In drawing on and developing personal skills and talents for the benefit of others they were able to recover a sense of meaning and continuity in their lives.

### *3. Developing and maintaining a continuing bond with the deceased person.*

In addition to aloneness, the obstacles to regaining a sense of control and continuity in life may be compounded by the relationship with and the life-style of the user prior to their death. Indeed, for many bereaved families the effects of having lived with the

person's substance misuse, including coping with the possibility that such misuse may eventually lead to their death (Orford et al., 2010), are profoundly destabilising.

Furthermore, as discussed, resources that enable some thread of continuity to be regained following bereavement, such as sharing with sympathetic others, may be unavailable, making it harder to recover fond memories and develop a continuing bond with the deceased in which comfort may be found. Whilst the creative responses so far discussed have achieved this through reaching out to and making links with the experiences of others in similar circumstances, some participants developed more private forms of creative expression that could help recover a positive and comforting connection to the deceased.

Margaret, whose son's substance misuse was linked to a psychological disorder, was unable to find support both before and after his death. Given what she described as "*professional indifference*", her experience of both his life and death was particularly undermining and destabilising. Having dedicated her life to 'saving' her son, when he died, not only did she feel abandoned by the system, but that she had inadvertently lost touch with herself and her remaining family. Yet, in spite of considerable self-recrimination and an absence of fond memories, she found her own way of recovering her connection to both her son and her own sense of integrity.

*Well, it started with our first Christmas without [him]. I decided I would write him a Christmas card... and I dated it and sealed it and put it in a tin. And then just after Christmas with what would have been his 24th birthday, I sent him a birthday card and put it in the tin. And then when it got to...the first anniversary, I wrote him a letter. And in the letter I told him about things that had happened since he died. ....So this tin is now*

*absolutely full of letters that I've written to [him] and I'm still writing to him. And that's the only way that I can kind of hold it together.*

Similarly, Eileen, in grieving her uncle's death, whilst finding support and reinforcement through supporting others, also pursued more private forms of self-support, through which she affirmed and preserved a continuing bond with him. Well documented in the reported experiences of bereaved people more generally (Hunsaker Hawkins, 1999; Francis et al., 2005; Valentine, 2008), these included writing songs, poems and letters to him and depositing these at his graveside.

*I write a lot of poetry about him. I write a lot of songs about him... I just go on my own and have a chat to him. You know it's weird having a one-way conversation. That was the biggest thing I had to learn to get over when I first start visiting his grave was that he's not talking back, but in a way I feel like he is anyway...because he understood me so well that I can almost imagine the kind of reply he would give me anyway. So it's definitely really important to just keep that going, like I will always visit his grave. If it's looking tatty, I would always clean it. I will always take him a little something and I will write him a poem or a letter, because he's still there. You know, he might not be here in body, but I'm sure he's around in spirit and I want him to know that.*

In reporting how they actively continued their relationship with the deceased person, both Margaret and Eileen represented continuing bonds as mutually reinforcing. In so doing they conveyed that, in a social context which may severely undermine the integrity of both bereaved and deceased, mourners may find creative ways of negotiating the situation to recover their own and their loved one's identity.

## **Conclusion**



In exploring creative responses to a stigmatised death and loss, this article has illustrated the complexities and ambiguities of the way people grieve. Such creativity could take public form, for example, providing support services for those living with or bereaved by substance misuse. It could be private, such as communicating with the deceased person through conversation, letters, poems and songs. It could entail a combination of both, such as applying private study to providing resources for raising awareness of addiction, publishing a book or making a film to dispel negative stereotypes. Yet, whatever the form, these examples have illustrated how such creativity was apparent in participants' negotiation of negative and dissonant cultural messages, which posed a severe threat to both their own and the deceased person's integrity and that of the relationship between them. Whilst participants suffered considerable trauma, including a profound sense of personal and social isolation, these negative effects were far from definitive of their experience. Rather, psychologically speaking, alongside pain and vulnerability, the resilience they conveyed could be viewed as evidence of post-traumatic growth (Joseph, 2012) as much as complicated grief disorder. Socio-culturally speaking, in relation to a particularly disintegrative loss, such resilience reflects the capacity for creative and constructive engagement with available cultural resources and constraints so as to rebuild identities and continuing bonds.

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**Table**

**Participant and deceased demographic Information**

<b>Participant/age</b>	<b>Deceased/age</b>	<b>Relationship of Participant to Deceased</b>	<b>Cause of Death</b>
Jennifer 37	Mother 63	Daughter	Alcoholic hepatitis
Katherine 24	Father 45	Daughter	Chronic alcoholism and blood clot
Eileen 24	Uncle 45	Niece	Heart attack
Angela 56	Son 21	Mother	Death by misadventure
Darren 23	Brother 29	Brother	Accidental overdose: poly-drug use
Margaret 57	Son 20	Mother	Cardiac arrest brought on by illicit drugs and alcohol